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Iowa/Nebraska Primary Care Association

Diabetes Focus Groups: Report on Barriers to Chronic Illness Care

For the Iowa Department of Public Health

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Introduction

The Iowa Department of Public Health (IDPH) requested the Iowa/Nebraska Primary Care Association (IANEPCA) to hold a series of focus group on *patient perceptions* of barriers to care for their chronic illnesses. In conjunction with the University of Iowa's Clinical and Translational Science Award (CTSA) community engagement program, four of Iowa's federally qualified health centers (FQHCs) have been doing work with their diabetic populations. The CTSA is a major funding stream from the National Institute of Health (NIH) to the University of Iowa. The Centers had previously identified two groups of patients with diabetes for study: those with Hemoglobin A1Cs under 7.0 (well controlled) and those with Hemoglobin A1Cs over 9.0 (poorly controlled). The four Centers (Community Health Care in Davenport, Primary Health Care in Des Moines, Siouxland CHC in Sioux City, and Peoples Community Health Clinic in Waterloo) agreed to hold a focus group from each of these two groups at each Center. Six focus groups were conducted in English at three urban sites and two in Spanish at a rural location (Marshalltown).

This paper reports the highlights of the findings. A more detailed analysis of the voluminous transcribed conversations may be conducted by CTSA researchers later.

Methods

Each of the four Centers employs a CTSA Coordinator, funded by the University's NIH award. The Des Moines Center chose to use its Marshalltown location to sample a rural population, and also chose to involve its Hispanic/Latino patients, since they make up a considerable proportion of diabetics in the State. The Coordinators and other staff met in Iowa City on May 27, 2010, for training in focus group methodology. Also, during this training, the Coordinators discussed the project protocol and Internal Review Board (IRB) process. The project protocol consists of the background, research design, methods, and data analysis. This document is located in Appendix A. Moreover, an IRB application was submitted to the University of Iowa IRB, which approved the project on 7/15/2010.

The potential population of patients in each category was identified by each FQHC from its diabetic registry. Patients were then called from this list to ascertain their interest in participation. Transportation was offered at some sites, as well as snacks, and small financial tokens to help patients with medications, proper food, etc. The number of attendees varied from site to site (ranging from 3 to 7 at each session). All sessions lasted 1.5 hours each. All discussions were audio-taped, after obtaining oral informed consent, so that the information could be transcribed and then coded by common themes and categories by University of Iowa CTSA faculty and staff.

Eight focus groups were conducted and completed by June 30, 2010. Focus groups have been used successfully to explore diabetes self-management among underserved populations and to examine perspectives regarding the management of patients with multiple risk factors. Patient group objectives included assessing: 1) diabetes knowledge and self care management, 2) goal-setting, 3) problem-solving, 4) preferences for receiving health information, and 5) experiences

at the FQHC in regards to diabetes care. These objectives informed development of the moderator's guide with open-ended questions and specific probes. The facilitator guide is located in Appendix B.

Participant's views may differ depending on their age, gender, socio-economic status, and racial/ethnic background; therefore, groups were segmented as much as possible to enhance participation. Also, we wanted to ensure adequate representation of men and younger adults because, according to the research literature, these groups tend to be more difficult to recruit. This approach enabled us to explore issues in detail and provided opportunities for themes to emerge that are unique to this population.

Typing the transcripts has proven challenging, as in most groups more than one patient would often talk at the same time, despite instructions not to. Completion of the transcripts and then coding the comments into categories of barriers were completed at the end of July. A qualitative data analysis software program (NVivo) was used to assist in the systematic exploration, organization, and analysis of the transcription data. The following is a description of this analysis.

Results

Audiotapes from these focus groups were transcribed verbatim in English and Spanish. The Spanish focus groups were transcribed in Spanish by an experienced Interpreter, who also provided a detailed summary report in English. The CTSA staff hand coded the data and conducted a preliminary content analysis. The data was later analyzed using NVivo. The project team then discussed key observations until consensus was reached about the main findings and conclusions.

Twenty patients participated in these focus group sessions (see Table 1). All patients identified themselves as Caucasian American, African American, and/or Hispanic/Latino. On average, patients were in their mid-forties. Patients were placed in one of two groups according to their latest Hemoglobin A1C levels (< 7 or > 9).

Table 1
Demographic characteristic of patients with diabetes

Focus groups (no.)	8
Age (years - mean)	46
Years with diabetes	7

First of all, the poorly controlled and well controlled groups differed in their general outlook on life. The well controlled seemed generally positive and more upbeat about their illness and life in general. The poorly controlled groups seemed to be more stressed and depressed. Among Hispanics, ALL patients said that their diabetes was caused by a traumatic life event – a “Susto”.

Diabetes Knowledge and Self-Care Management

Participants expressed a wide range of impressions about diabetes and its causes, including a perceived susceptibility due to ethnicity/race and heredity. Some patients viewed diabetes as an inevitable consequence of being Hispanic or having a family history of diabetes. Many could

identify several family members who have diabetes. Controllable factors, such as diet (sugar and carbohydrates) were also described by patients, who believed they had diabetes because of what they ate. Stress and depressions was also identified by patients in all eight focus groups as a cause of diabetes, with the belief that the more anxious or depressed one was, the more chance one had to contract the illness or worsen its symptoms.

Some patients expressed a perception of limited capacity to manage their diabetes addressing the ongoing difficulty of breaking familiar eating habits and usual routines as key issues that were on their minds. For example, some patients understood the importance of dieting and exercise, but also acknowledged the challenges of translating this understanding into practice. These challenges were described as limited time to exercise, family not understanding diabetes (and the foods that one should and should not consume), and finances, which in turn did not produce positive results in their general glucose control and well-being. Consequently, depression, anxiety, and stress were common among patients, who openly discussed their frustration over expected outcomes.

Goal Setting

Patients were asked if they had learned to set goals as a way to manage their diabetes and several reported that they managed in their own way. Many patients talked about losing weight, dieting, and exercise, but did not know how to accomplish these goals. Several reported feeling stressed and “burned out” from not seeing expected results in their weight and glucose control.

In other instances, some patients reported their providers being the sole person who would assist them in setting goals; however, patients were confused about how to accomplish short- and long-term goals. Another common concern was polypharmacy and how taking medications for several co-morbidities (i.e. hypertension, hyperlipidemia, heart disease) “probably is affecting my ability to lose weight”, as described by one participant.

Problem-solving

Some patients discussed how families can be supportive, especially during challenging situations. However, some stated that family members may not always understand or be sensitive to the foods one consumes or may not adjust/make changes to certain meals. This theme was perceived throughout several focus groups in which patients had limited choices about food preparations or where to obtain healthier foods.

Preferences for receiving health information

Many participants enjoyed the focus group format and requested to hold more group sessions as they seemed helpful to discuss sensitive and challenging issues with managing diabetes. Overall, there appeared to be a preferred in-person education format, but many participants also stated that they enjoyed receiving pamphlets or booklets about diabetes.

When patients were asked about what they do when they receive educational material that was confusing or unclear, most of them indicated that they called the clinic nurse or ancillary staff for clarification. A few mentioned that they use other resources such as the library, Internet, phone, or other written materials. However, participants indicated that they mostly rely on health

care providers for information. Others mentioned that they primarily talked to their friends and family for information.

Experiences at the FQHC

The centers were able to learn lesson from the focus groups to improve the care provided. For example, at least one patient reported it had been hard to get an appointment when they were ill, and they had to go to an emergency room for care.

Other common themes were that they did not receive enough education on diet or the medications they were prescribed. Many felt that the cost of proper food and medication was beyond their fiscal means. Also, methods of transportation were problematic as many did not have the financial means to travel to appointments or to grocery stores to purchase healthier foods.

Literacy Issues

A measure of reading skills was assessed by using the Single Item Literacy Screener or SILS. The SILS is a single item instrument designed to identify patients who need help with reading health-related information. The instrument asks one question “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” with possible responses ranging from “1” (never) to “5” (always). The authors identified the cut-off point as “2” in order to capture all patients potentially in need of assistance. See Appendix C for SILS instrument.

The majority of patients answered this question on a separate form before or after the focus groups. No personal identifiers (i.e. name, social security number) were requested. The responses to this question varied widely from “1” (never having someone help when reading health-related instructions) to “4” and “5” (often or always needing assistance with reading health-related information). Since we had a small sample size in each focus group, it is difficult to generalize findings to the population at each FQHC. Also, it is difficult to determine if the majority of patients have or do not have difficulty reading health-related documents and if they do, who might assist them in reading these instructions. However, this information is key as we develop culturally-sensitive and literate appropriate educational materials at each FQHC. Also, our Quality Improvement committee might be able to better assess and evaluate instructions developed for patients with our i2i program.

The next step to explore literacy issues would be to recruit a larger sample of patients to obtain responses to the SILS instrument. This information will assist us in assessing the magnitude of literacy issues.

Conclusion

This qualitative project offers insights into the knowledge, attitudes, practices, beliefs, and perceived barriers facing underserved populations in Iowa regarding diabetes self-management. These findings add to the literature on strategies to better address an illness that requires complex and multi-disciplinary management. This information may assist in the development and

implementation of future culturally-congruent and lifestyle-based interventions aimed at promoting active patient self-management of diabetes, a key component of current treatment model to improve care outcomes in this vulnerable population.

Practice Implications

This focus group data revealed a number of known and hidden themes that may assist providers in FQHCs understand why current diabetes self-management models do not fully address the needs and priorities of underserved patients. One element of care reported by patients that may not be adequately reflected in current treatment approaches in this population was that stress plays a key role in how patients manage diabetes. The central role of family in goal-setting and problem-solving was a second. The desire for more information was also prominent, with a variety of approaches probably required to meet this need.

A reasonable next step would be to interview FQHC providers to obtain their perspective on how their patients with diabetes manage their diabetes and solve daily challenges and problems. Another step would be to develop a center-based diabetes self-management guideline that providers (i.e. care managers, educators) may use to educate patients on short- and long-term goals that include family members and community resources. Furthermore, counseling and psychotherapy may be helpful approaches that could be integrated in diabetes self-management to assist patients who suffer ongoing stress and anxiety. There appears to be an opportunity to assist patients in coping with emotional and psychological aspects of adjusting to life as someone with diabetes and during challenges. Several stated that just talking about diabetes during the focus group discussions was beneficial.

Appendix A

Project Proposal

Introduction

The Iowa/Nebraska Primary Care Association's (IANEPCA) Center for Value in Healthcare offers the following outline of a proposal to gather, via focus groups, information from the patient's perspective on barriers to care for their chronic disease.

IANEPCA has an ongoing relationship with the Clinical and Translational Science Award (CTSA) Community Engagement component at the University of Iowa for research and evaluation purposes. The CTSA is designed to bring community input into the research agenda and help close the loop by getting research into practice in a timely manner.

Each of four participating CHC members of IANEPCA has a CTSA Coordinator on site to help with this project. Additionally we have 160 patients with diabetes who will be ideal for this project. These patients were chosen for an earlier survey and are being tracked in our comprehensive care management software (a registry). Half had Hemoglobin (Hgb) A1Cs over 9.0% and half under 7.0% at entry into the tracking software about a year ago. Key barriers to be probed in the focus groups will be ascertained beforehand in concert with our CTSA colleagues. We see this information as valuable to us in direct patient care, in that the findings about the barriers may prove useful to our Centers in improving care.

The four Centers are in Davenport, Des Moines, Sioux City and Waterloo. We should be able to have a variety of racial and ethnic groups sampled. Many will be uninsured or on Medicaid/Medicare. The Iowa Department of Public Health (IDPH) requested a focus group to be conducted at a rural site. Marshalltown will be the rural CHC.

Purpose

The purpose of this project is to use a focus group format to explore individual, educational, and system barriers to and identify effective strategies for diabetes self-management in underserved adults (+18, in good and poor glycemic control) with Diabetes Mellitus (DM) type II in three urban (Davenport, Sioux City, and Waterloo) and one rural (Marshalltown) Community Health Centers.

The goal of the project is to highlight individual, educational, system, and infrastructure needs or changes in clinical practice that would facilitate the integration of more effective diabetes self-management.

Background

Diabetes is a major public health concern and financial burden in the United States. Research shows that, for underserved individuals with diabetes, adhering to programs of self-care is often problematic. Despite the potential for improved metabolic control and quality of life, little is known about the barriers and effective strategies that people with diabetes successfully use to incorporate plans of care into their lifestyles.

Management of diabetes is complex for patients and providers and requires good patient-provider communication skills. Most effective communication resources (e.g. handouts, internet information) are heavily reliant on literacy and linguistic skills. The myriad physiological and behavioral issues involved mean multiple health education topics for patients, which may be particularly difficult for patients with less education and poor literacy skills. Research has

documented that the prevalence of diabetes is inversely related to educational status and that difficulties in comprehension result in incomplete understanding of the disease and/or its management for such individuals.

Research design

A qualitative research approach using focus group interviews will be used to explore barriers to achieve diabetes self-management and effective strategies to counteract these problems. A qualitative research approach can provide useful insight from individuals who may be reluctant to be interviewed, believe they have nothing to say, or may have poor reading skills. Qualitative research is also an effective approach when trying to identify cultural issues. Focus groups can also help identify, examine, and understand personal beliefs, motivations, skills, and practices.

Methods

Participants:

Two focus groups will be conducted in each of the four CHCs (8 total) with urban and rural underserved patients with DM type II (in the well-controlled and poorly-controlled group) who had participated and completed two surveys (Patient Assessment of Chronic Illness Care/PACIC and Summary of Diabetes Self-Care Activities/SDSCA) for a previous CTSA Diabetes Survey project about a year ago. For that study, participants (40 from each site) were recruited via each CHC's diabetes i2i Tracks registry. Inclusion criteria included: 1) identifying poorly controlled patients with DM (Hgb A1C > 9.0), 2) identifying well-controlled patients with DM (Hgb A1C < 7.0) in each Community Health Center (Davenport, Des Moines, Sioux City, and Waterloo) and 3) each patient must have had at least two visits within the past year (1/1/2008 – 12/31-2008). Each Coordinator obtained a list of patients with DM who had an appointment in May and June, 2009 from i2i registry.

Both surveys (PACIC and SDSCA) were then collected from patients at the time of their scheduled visit. The diabetes i2i registry now contains two new Patient Profile Items under "other". Under this category each participant was identified as follows: Project < 7.0; and Project > 9.0. This allowed this sub-population of patients with DM to be tracked for future quality improvement or research projects.

For this project, participants will be selected from the pool of participants that enrolled in the Diabetes survey project. Our goal is to have each focus group composed of 8 to 10 patients with diabetes. Because it is likely that several patients who agreed to participate in the CTSA Diabetes Survey Project may not show up for the discussion, 15 patients will be recruited for each group (anticipating that 10 would attend, 8 total sessions: 4 well-controlled and 4 poorly-controlled groups). Each focus group will last up to 90 minutes, and a period for refreshments will be provided.

The Coordinator will call the patients who participated in the first project to ask if he/she would be interested in participating in a focus group discussion about chronic care barriers and facilitators. If the patient agrees, he/she will be provided with the time and date of the focus group discussion. Participants will receive \$20 for participation and to defray any travel/childcare expenses to attend the focus group. Written informed consent will be obtained from each participant and confidentially strategies will be discussed before each focus group session.

Demographic and Disease-related Information:

Information on age, gender, diabetes duration, and current diabetes treatment will be obtained by each participant from the Focus Group Demographic and Survey Form. To confirm that the participant's assignment to the well-controlled or poor-controlled focus group is correct, each participant's most recent A1C value taken within 3 months of the scheduled focus group will be obtained from the electronic medical record.

Focus group Sessions:

The focus groups will be led by the CHC's Coordinator in a private meeting room at each CHC. All sessions will be conducted in English, with the exception of Marshalltown – these sessions will be conducted in Spanish if enough Spanish-speaking participants. A consent and confidentiality form will be read to all participants and oral consent will be obtained before beginning the group discussions. A measure of reading skills will be assessed by using the Single Item Literacy Screener or SILS, which is embedded in the Focus Group Demographic and Survey Form. The SILS is a single item instrument designed to identify patients who need help with reading health-related information. The instrument asks one question "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" with possible responses ranging from "1" (never) to "5" (always). The authors identified the cut-off point as "2" in order to capture all patients potentially in need of assistance. See Appendix B for SILS instrument.

The Coordinator (and co-facilitator) will be responsible for audio-taping the group discussions, taking notes during the group sessions, obtaining oral informed consent, collecting the Focus Group Demographic and Survey Form, and distributing compensation to participants following the sessions. The Coordinator may begin the focus group interview with an introduction, stating, "We are interested in the types of problems or barriers people have with taking care of their diabetes and how people handle these problems". Also, the Coordinator will ask probes to each open-ended question in the Interview Guide, particularly to elicit examples of problem situations pertaining to areas of the diabetes regimen, including medication taking, diet, exercise, self-monitoring of blood glucose, and managing complications. At the end of each focus group sessions, the Coordinator may give a summary (if time allows) of the main points expressed during the group session, which will give participants the opportunity to correct or modify the main points that were discussed and concluded.

Interview Guide:

The interview guide uses an open-ended question format. See Appendix A.

Barriers discussed in the Guide were obtained from previous studies, such as: individual, familial, educational, system, environmental, and other.

Logistics

Materials needed for each focus group: Interview guide, tape recorder, tapes, mics, extra batteries, cards for name tents, food, gift certificate, Focus Group Demographic and Survey documents, informed consent document, and Kleenex.

Data analysis

The focus group audiotapes will be transcribed verbatim by a Transcriptionist.

A qualitative data analysis software program (NVivo) will be used to assist in the systematic exploration, organization, and analysis of the transcription data. Responses that do not answer any question in the focus group interview will not be coded. Data will be stored in a secured database at each of the CHCs in a locked room and analysis will be conducted in the Office of Nursing Research after IRB approval (pending).

Appendix B

Chronic Care Barriers: Facilitator (Topic) Guide

I. Warm-up and Explanation (10 minutes)

- A. Introduction
 - a. Thanks for coming.
 - b. Your presence is important; you are representing many patients.
 - c. Explain and read Informed Consent/Confidentiality document No signatures needed.
 - d. Describe importance of information they are providing; may help other patients with diabetes receiving care at the CHC.
 - e. Describe what a focus group is – to learn about your beliefs and viewpoints.
- B. Purpose
 - a. We will be discussing your experiences in regards to barriers, problems, and challenges to managing your diabetes and how we may be able to provide better care/information to you.
 - b. I'm interested in all your ideas, comments, and suggestions.
 - c. All comments - both positive and negative - are welcome.
 - d. Please feel free to disagree with one another. We want to have many points of view.
- C. Procedure
 - a. Explain that session is being recorded. All comments are confidential and will be used only for project purposes. Nothing will be reported to your primary care provider or anyone else. This session will last 90 minutes.
 - b. I want this to be a group discussion, so don't wait for me to call on you. Please speak one at a time so that the recorder can pick up everything.
 - c. We have a lot of ground to cover, so I may change the subject or move ahead. Please stop me if you want to add something.
 - d. Give Focus Group Demographic and Survey form. Please complete this short demographic and survey form. Please do not write your name – your answers will remain confidential and private.

TURN ON TAPE RECORDER

- D. Self Introductions
 - a. Ask each participant to introduce him or herself, but only use first name. Tell us your name and something about yourself.
- Probe:** *What neighborhood are you from? (QUESTION ASKED IN EVERY SESSION)*
- Are you employed, in school, or work at home?*
- Do you have any brothers or sisters?*
- Do you have children?*

II. Knowledge of Diabetes and Self-Care Management (15 minutes)

- A. What is diabetes? *Do you see a connection between high sugar and complications (circulation and nerve damage, damage to their eyes, kidney damage)*
- B. How do you think you got diabetes?
Probe: Do you feel that lifestyle or diet caused you to get diabetes?
Do you feel it just happened to you and there was nothing you could have done?
- C. What is it like living with diabetes?
Probe: Diet and exercise
Home glucose monitoring
Taking medications
Side effects of medications
- D. How often do you need to see your primary care provider? Come into the clinic?
Probe: Do you know WHY you need to come in for an appointment?
How often would you like to come in for an appointment?
- E. What special things do you need to do to take care of your diabetes?
Probe: What does "A1c" mean to you?
Diet, exercise, medications
Home glucose monitoring
- F. What are some of the barriers that you have when trying to take care of your diabetes?

III. Goal setting (15 minutes)

- A. Do you set goals related to diabetes? How is it done?
- B. Who helped you set these goals?
Probe: diabetes educator, health educator, or provider?
- C. How often are those goals reviewed?
- D. What has worked well with setting goals?
- E. What are the major barriers to setting goals?
- F. What has been the most difficult thing for you to accomplish in regards to your self-management goals?
- G. Would you like support in setting goals?
- H. How important is family involvement in setting priorities or goals?
- I. How important is setting goals to manage your diabetes?

IV. Problem solving (15 minutes)

- A. What is hard for you about taking care of your diabetes?
Probe: money, transportation, time, appointment availability, plans to exercise, knowing food choices, diet, or family issues.
- B. How do you deal with problems that come up with taking care of your diabetes?
- C. What do you do when the same problems come up over and over again?
- D. What do you do when new problems come up?
- E. What types of things help you handle problems with your diabetes?

V. Preferences for Receiving Health Information (10 minutes)

- A. When you get information about diabetes, what sort of format do you prefer that information is given to you in? How do you learn best?
Probe: Brochures
Posters
Internet/website
E-mail
Thorough 1:1 discussion with clinic staff
By telephone
- B. Who do you trust the most to give you information about diabetes?
- C. Diabetes information can be very complicated and confusing. If you need to ask for clarification or help with understanding the information you receive, who is that person?
- D. What specific topics would you like to learn about?

VI. Experiences at the Community Health Center (20 minutes)

REITERATE CONFIDENTIALITY – it is okay to share, your name will not be mentioned or recorded and will not affect the care you receive at the CHC.

- A. Describe either a good or bad experience you have had receiving diabetes information at the CHC. What made the experience either good or bad?
- B. What do you like about current diabetes education efforts at the CHC?
- C. What don't you like about current diabetes education efforts at the CHC?
- D. What kinds of information that you have received at the CHC have NOT been helpful?
- E. If you could change anything about how you receive diabetes information at the CHC what would that be? We would really like your advice about how you would like to receive information about diabetes at the CHC.

Probe: Are there specific barriers to receiving diabetes care?

VII. Closing (5 minutes)

- A. Before we finish, I'd like to go around the room one more time just to see if there's anything else you'd like to say about the topics we've discussed (Reflect on prior comments).
- B. Thank you so much for coming. Your time is much appreciated, and your insights have been very helpful.
- C. Provide \$20 certificate.
- D. Give American Diabetes Association booklet "Choose to Live: Your Survival Guide".
- E. List three (or more) themes that you discovered throughout the focus group and share with Jimmy Reyes via email.
- F. Collect all forms/documents. Give tape to Transcriptionist.

Appendix C

Single Item Literacy Screener Instrument

How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

1 (Never) 2 (Rarely) 3 (Sometimes) 4 (Often) 5(Always)

Scores greater than 2 are considered positive, indicating some difficulty with reading printed health related material.

Strengths:

- Brief and therefore practical for use in clinical practice.
- More a direct assessment of need than an assessment of skill.
- Simpler than an estimate based on demographics.

Limitations:

- False negatives are possible because of participants not recognizing that they need help with reading, feeling ashamed, or not understanding the question.

Citation:

Morris NS, MacLean CD, Chew LD, and Littenberg B. The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Family Practice*. 2006, 7(21).